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Chair

Mr. Bill Casey

Standing Committee on Health

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● (1530)

[English]

The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)): We'll call our meeting to order. Welcome, everybody, to meeting 104 of the Standing Committee on Health. Pursuant to Standing Order 108(2), we're going to study organ donation.

Mr. Webber has brought this to our attention several times. I think we agreed to do it quite a while ago. We're glad to get to it.

Today for witnesses, we have from B.C. Transplant by video conference, Leanne Appleton, provincial executive director; and Edward Ferre, provincial operations director. From Canadian Blood Services, we have Dr. Isra Levy, vice-president, medical affairs and innovation; and Amber Appleby, acting director, donation and transplantation. We also have Trillium Gift of Life Network, Ronnie Gavsie, president and chief executive officer.

Welcome, everyone.

We're going to ask each of you to make a 10-minute opening statement.

We'll start with our friends from B.C. Transplant.

Ms. Leanne Appleton (Provincial Executive Director, BC Transplant): Thank you very much for this opportunity.

My name is Leanne Appleton. I am the provincial executive director for B.C. Transplant, the organization with a provincial mandate for leadership and governance of organ donation and transplantation here in British Columbia. We are a part of the Provincial Health Services Authority.

Increasing organ donation is one of our key strategic goals, and we continue to build the infrastructure necessary to maximize organ donation potential from both a clinical and a public perspective. We've taken a multipronged and clinical systems approach to achieve this, based on what is globally recognized as best practice for increasing organ donation and aligned with national leading practices led by Canadian Blood Services.

B.C. started over two decades ago by establishing a strong foundation with two key elements. The first is mandatory referral legislation, which mandates all deaths or impending deaths in hospital to be referred to B.C. Transplant for consideration for organ or tissue donation. This type of legislation is viewed broadly as a key factor that contributes to higher donation rates.

The second element is the organ donor registry, now in its 20th year, which was the first in Canada, and the first to offer residents the ability to register completely online. It provides a legal record of a person's organ donation decision—yes or no—and is tied to a person's personal health number. It enables our organ donation team to share the decision with the family of a potential organ donor. This can help ease the burden of making a decision in a tragic moment.

With these foundational pieces in play, over the last few years we've focused on implementing other system components that are recognized nationally and internationally as fundamental and best practice for high donation performance.

My colleague Edward Ferre, B.C. Transplant's provincial operations director, will now speak to this.

Mr. Edward Ferre (Provincial Operations Director, BC Transplant): Thank you, Leanne, and to the committee for this opportunity.

I'll touch on five comments.

First, we've developed strong partnerships with the in-hospital critical care community's support health care professionals in offering the option of organ donation as a part of quality end-of-life care. In B.C. we have donation committees at the provincial health authority and hospital levels to review compliance to regulations that identify opportunities for quality improvements. A vital element of this is a robust education strategy for staff in emergency rooms, critical care units, and operating rooms. We provide education, tools, and support to hospitals with the goal of ensuring that all families faced with a tragedy have the opportunity to consider organ donation.

Second, we now have a network of system-wide donation specialists and in-hospital donation coordinators, who work collaboratively with critical care donation physicians and regional hospital-based critical care teams to support organ donation at the hospital level. Our 24-7 team of organ donation coordinators receive referrals from across B.C. and provide expertise in supporting families, the consent process, and donor management. Our organ recovery team travels to hospitals throughout the province to recover organs. This is a patient and family-centred model that allows organ recovery to occur at the hospital where the donor is located and allows families of donors to be with their loved ones for as long as possible.

Third, we are also working with hospitals across the province to expand organ donation opportunities by offering donation after cardiocirculatory death in a steadily increasing number of hospitals, including small hospitals outside of B.C.'s major urban centres. This offers another end-of-life option for families facing the sudden death of a loved one in hospital, and it also expands the number of potential organ donors.

A fourth fundamental infrastructure component for high-donation performance is the implementation of national leading practice recommendations led through the Canadian Council for Donation and Transplantation and Canadian Blood Services. These include standardizing guidelines for neurological determination of death, standardized guidelines for donation after cardiocirculatory death, donor management guidelines, donor family support and effective requesting as part of quality end-of-life care, and donation after medical assistance in dying.

The fifth and final component is public awareness, understanding, and support for organ donation, which are all critical to the success of an organ donation system. To that end, we have a strong public awareness, education, and community relations program. Underpinning this program is the provincial organ donor registry. While it serves a clear purpose for our organ donation team working with families' potential donors, the registry serves an additional public engagement purpose as a tool to enable public conversations about organ donation. Registering a decision is the key call to action at the heart of most public awareness campaigns on organ donation in B.C. and across Canada.

Where we've had additional success is through partnerships with the organizations that serve as touchpoints for the citizens of British Columbia. The first is with Service B.C., which has 62 locations across the province where people can access support for programs and services offered by the provincial government. The second is with the Insurance Corporation of British Columbia in their driver licensing offices, where people obtain or renew their driver's licences and service cards. When people visit these offices, they are asked about organ donation, and then they may have a conversation about the subject and register their decision. The majority of registrants in the organ donor registry now come through these two partnerships. In the year of the full ICBC partnership, decisions registered in the registry increased by 15%. More than 1.2 million British Columbians have registered their decision since the registry was established.

We also maintain a robust program of public education and outreach, which involves advertising, media relations, and social media engagement aligned with national initiatives such as National Organ and Tissue Donor Awareness Week, at the end of April. We have a robust network of volunteers, which includes organ donor families, living organ donors, and transplant recipients, whose stories drive awareness and support for organ donation. These volunteers are highly engaged in our community and workplace events and campaigns.

● (1535)

The work around public engagement and awareness helps to normalize conversations about organ donation and transplant in our communities and within families, so it can be seen as an acceptable and normal end-of-life option.

Ms. Leanne Appleton: B.C.'s investment in the implementation of these deceased donation strategies has led to a 150% increase in referrals of potential donors from hospitals between 2013 and 2017. B.C.'s deceased donor rate has increased by 81% from 67 donors in 2013 to 121 donors in 2017. The year 2017 was a record in B.C. for the number of donors, a year in which a record 479 lives were saved through transplants.

Our province is now one of the leaders in Canada for deceased donation. I have to acknowledge that this success is the result of the collaborative efforts of an interdisciplinary team of health professionals. Advancing organ donation is only possible with the team effort, commitment, and skill of many highly trained professional physicians and specialists.

Before I conclude I want to note that, while our focus today has been on deceased donation, we also have a strong clinical infrastructure for living donation, which has made B.C. one of the leaders in Canada. Living-donor kidney transplants represent the greatest potential growth area for better access to transplant for patients on the kidney wait-list. The success of B.C.'s program is due in part to the development of a fast-track assessment process to screen potential donors, participation in the national kidney paired exchange program, and the highly sensitized patient registry managed by Canadian Blood Services.

There's always more progress to be made for both deceased and living donation. We are working to ensure we do not miss British Columbians who would have wished to be donors, by developing a comprehensive and robust medical record review process together with our partner hospitals providing audit and feedback. New technologies also present opportunity for improvement, including ex vivo lung perfusion, which we are exploring in B.C. We also have ongoing initiatives to increase living kidney donation, and particularly pre-emptive living kidney transplant.

Thank you very much for taking the time to listen to our input today.

● (1540)

The Chair: Thank you very much. You had six seconds left on your time.

Ms. Leanne Appleton: It's wonderful timing.

The Chair: You did well. Thank you.

Now we move to the Canadian Blood Services, with Dr. Levy for 10 minutes.

Dr. Isra Levy (Vice-President, Medical Affairs and Innovation, Canadian Blood Services): Thank you very much for the introduction.

I'm Isra Levy. I'm the vice-president of medical affairs and innovation at Canadian Blood Services, and there I work with our organ and tissue donation and transplantation team, supporting and coordinating Canada's provincial and territorial donation and transplantation organizations, programs, and clinicians in their critically important and life-saving work at the bedside.

I am pleased to be joined by my colleague Amber Appleby today. Amber is the acting director of donation and transplantation at Canadian Blood Services, and will be available for questions.

It's also a privilege to appear together with some of our partners, not only Trillium Gift of Life and B.C. Transplant, but also later this week, I'm aware that you'll be hearing from another major partner, the Canadian National Transplant Research Program. I think this exemplifies the degree to which we see the collaborative nature of this exercise as being the only way to success on the way forward.

It's trite to say, and I know you are already aware of it, but for every patient in Canada who does receive an organ transplant, which is obviously life-saving, there are two more on the waiting list. Every year we know that people die while waiting, in fact, probably more than one every two days. At least 200 Canadians died while waiting for a suitable transplant opportunity last year.

There is a lot to do, but there's real cause for some reflection on progress to date. Canada's deceased donation rate, which is the organ donation numbers by deceased donors, last year was 21.8 donors per million population, which is a really marked improvement when you compare that with the last five and 10-year periods, but it is still less than a half the rate of some of the highest-performing countries around the world.

Our living donation rate, on the other hand, compares quite favourable internationally, but there we are seeing challenges, and we've seen declines year over year in the last few years when you look across the country.

In recognition of some of the deficits in the system, going way back now, some changes have been made by you and by your predecessors. In 2008, Canadian Blood Services was asked by federal, provincial, and territorial ministers of health to help strengthen the system across the country, particularly in helping jurisdictions support each other and increase access to transplant opportunities that may cross jurisdictional boundaries. An equity of access underpinning was very much at the forefront of the work when we got involved in it.

Of course, organ donation and transplantation are unique and highly specialized, interdependent areas of practice, and they're episodic and resource-intensive. The degree of clinical, provincial, interprovincial, and national co-operation that's required to facilitate the successes that I referred to are really quite significant. Certainly at CBS we're proud that we can be facilitatory and instrumental in supporting these activities.

The partnership that we enjoy with provincial and national stakeholders is informed by successful international models, and together with our provincial and clinical partners, we've developed a plan to improve system performance. That plan has been implemented, at least in part. We've been helped by federal, provincial, and territorial funders for support for different components of the plan, and it has underpinned those successes. As I've mentioned, we've shown a sustained improvement in deceased organ donation, which is a significant and important achievement for the country.

Leanne mentioned that we've also had significant successes in living donation in the coordination at the national level, through what we call the kidney paired donation program.

● (1545)

I think it is worth just reflecting that the partnership, which was launched in 2008, has created more than 575 transplant opportunities for patients with incompatible but living donors. When one thinks about it, that's an average of more than one transplant every week for each week in the last 10 years, which has been a result of this co-operative program. Those are transplants that would not have occurred without the program that connects the incompatible pairs from across the country to find suitable donor exchanges.

Of course, another milestone that I know many of you helped us celebrate last week was a milestone of national collaboration. It was the achievement of the 1,000th kidney transplant facilitated by the interprovincial organ-sharing work that we do.

We know that knowledge of performance drivers, leadership, and coordination at all levels of the system have been and will continue to be basic success ingredients for continued improvement of the national system, but of course you're here because you know that much remains to be done. Certainly when I reflected on what we might bring to you that would be helpful, I thought it was important to emphasize the inescapable and regrettable fact that it does matter where one lives in this country in terms of the probability of being able to be either a donor or a recipient.

There's no question that performance varies across jurisdictional and even institutional programming. That is something we can collectively put our minds to, I think. The role and scope of activities across jurisdictions with donation programs working with hospitals facilitating the donation process does vary. We see some programs responsible for deceased donation only. We see others include aspects of living donation, transplant services, etc. Some will include tissue donation. Others don't. Some have no deceased donation program at all. Others have no living donation program.

The challenges of this interjurisdictional inconsistency are many. It's important, of course, because we must remember that only a small percentage—and it's probably less than 2%—of deaths in Canada occur in a way that can actually lead to the individual becoming a donor. So the rarity of the potential donor is such that it really behooves us not to miss the opportunity, when we have the opportunity, to use that donation of an organ or set of organs.

I've mentioned the living donation programs that have also been added to the deceased donation programs in order to increase the frequency, and we've certainly seen that provinces that invest in the infrastructure for deceased donations and that also invest in increasing their living donation rates, see the returns in increased transplants for their patients.

I think one of the things we can collectively do is seek to make the opportunities available for those who want to donate, ensure the system can assess potential living donors as well as promote deceased donation, and allow them to donate in reasonable timelines.

We at CBS, with the partnerships, really understand that the degree to which donation and transplantation services are organized and operated in each province is something that we can ensure gets shared. It is foundational to assessing the impact on access to care and improving performance. Doing that from a national focus, I think, requires that jurisdiction-specific challenges be understood and addressed, and that jurisdictions and institutions and programs be supported to ensure that when donation opportunities arise they are not lost.

In future, then, I think what we would offer is that Canada's performance in donation and transplantation should be measured based on inputs, certainly, such as the ones I've mentioned—maximizing living and deceased donors—but also on outcomes.

● (1550)

We should be starting to turn our attention to facilitating the greatest number of transplants possible for patients who need them, but also to do this as quickly as possible and ensure the best possible clinical outcome from the best possible match to improve the quality of life for the long term.

Therefore, the underpinning research of our partners in CNTRP, the research part of the this partnership, is all the more important. The recipe for system improvement can continually be looked at and improved upon, but we know that when key ingredients are implemented, marked improvement happens.

Based on our experiences as a coordinating body for these donations and transplants in Canada, we would recommend that national priorities focus on strategies to advance interprovincial organ sharing, that we seek to advance living and deceased donations by assisting jurisdictions in their implementation challenges. Together, these elements will enhance system performance. There's a role in national system performance measurement. That measurement will help to drive increased performance and quality and promote an accountable system.

Opportunities for federal support I believe include facilitating referral of potential donors, education and awareness, and promoting optimal and consistent practices across jurisdictions.

Focusing on those measures to improve consistency will ensure all stakeholders are invested, and that donors and organs are not lost to avoidable factors, which results in harm or even death for a transplant candidate who then does not get the successful transplant. A national approach to leading practice development, to public and professional education, to system performance measurement and improvement, and to coordination of advanced interprovincial organ sharing, we think, would be cost-effective, is cost-effective, and will continue to deliver ever-better outcomes for Canadians.

I've probably gone over the 10 minutes. Sorry about that. I'll conclude by saying that in the last 10 years we have seen considerable progress in advancing the performance of the organ and tissue donation and transplantation system in Canada. The national collaborative work, which we've been privileged and proud to facilitate, has helped to increase those rates. It's helped therefore to save and improve lives, and it's led to avoided costs for the health-care system.

We are very encouraged. We know that Health Canada officials have embarked on collaborative efforts with provincial and territorial officials to identify and advance critical next steps, to further define roles and responsibilities, and to examine what additional opportunities applied nationally might have the most significant impact. We're grateful for that. We're grateful for your ongoing interest and support.

[*Translation*]

Together, we can save lives.

[*English*]

The Chair: Thank you.

Now we go to Trillium Gift of Life Network.

Ms. Ronnie Gavsie (President and Chief Executive Officer, Trillium Gift of Life Network): Thank you.

Trillium Gift of Life Network is the Ontario agency which, under provincial legislation, is responsible and accountable for planning, promoting, coordinating, and supporting organ and tissue donation and transplant, and for participating in that process 24-7.

Since our inception, close to 17,000 Ontarians have received life-saving organ transplants. On behalf of Trillium's board of directors, its management, its staff, our partners in the health care community, donor families, and recipients in Ontario, thank you for the opportunity to participate today.

The strategy to increase organ donation very simply put is twofold: first, inspiring and encouraging the public to consent to donation at end of life; and second, organizing and structuring the local health system to ensure all donation opportunities are identified and appropriately followed through. Both elements are key to maximizing access to organ donation, and the federal government does play a role and can further play an important role.

Based on Trillium's experience, I will bring you today three recommendations for the role of the federal government in improving access to organ donation.

Recommendation one is to develop and implement a national, sustained, multimedia public education campaign. Improving access to organ donation must start with increasing the number of organ donors. One of the most proven ways of increasing organ donors is through public awareness, which leads to consent to donate. Families of potential donors who are registered overwhelmingly honour their loved one's wishes, but in absence of registration, that consent rate falls dramatically.

Following the tragedy in Humboldt, and the revelation that one of the victims of that tragedy had registered for donation and went on to save six lives, registration for donation skyrocketed right across the country. When Canadians are reminded of the altruistic nature and the life-saving benefit of donation, they respond. They take action. But they were jolted into it.

The Spanish model is one to look at. Spain boasts the highest organ donation rate in the world. Their authorities, their physicians, will say that this is not attributable to presumed consent—it is not. It is attributable to the structure they have on the ground, and most importantly, to the constant presence of organ and tissue donation in their media. Through this persistent presence in the media, a culture in which organ and tissue donation is seen as being an integral and expected part of end-of-life care has been established. We too can do that.

Recommendation two is to increase opportunities for organ and tissue donation registration using federal channels. Include and promote opportunities for donor registration through Service Canada and all of the high-volume public transactions at the federal level: obtaining and renewing passports, voter registration, filing of tax returns. These channels can drive web-based links to the donor registration mechanisms that are already in place in each province. There is no need to collect or transmit any personal patient information. It avoids duplication. It avoids the creation of any new infrastructure that already exists in the provinces.

Increasing the number of opportunities and portals for Canadians to register in their home province will help increase donor registration, improve consent rates, and build a donation culture in Canada.

● (1555)

Recommendation three is based on the proven fact that teams of qualified and uniquely trained resources, working in fine-tuned harmony on the ground at the local level, are mandatory if Canada is going to increase organ donation. No matter what else is done, without these trained, committed, accountable patient-facing professionals, there will be no increase in the number of donors. These professionals are intensivists and critical care nurses in the hospital ICUs. They include donation physicians and donation coordinators, all accountable to a single designated entity.

This on-the-ground team cannot be put in place and sustained from afar. This is a provincial responsibility. However, we recommend that at the federal level there be a prioritized, nationally supported initiative that promulgates Canada's existing assets, it's best-in-class education programs, practical information resources, and collateral, right across the country.

Every province will have to make its own decision on creating and sustaining these on-the-ground teams, but for those who are prepared to do so, collateral is ready. We have centres of excellence in Canada. We have them in British Columbia, in Quebec, and in Ontario. A national prioritized initiative will facilitate the sharing of Canada's turnkey leading practices. The pace of promulgation and ready-made assets will be faster than creating new materials, or customizing into one set of collateral for all.

It is Trillium's experience that time matters. Canadians are dying on the wait-list every day. The more provinces that have teams waking up each day focused on nothing but organ donation, the faster we can promote these ready-to-use assets and the faster we will save lives.

In summary, we recommend a federal role supporting development and implementation of a hard-hitting, multimedia public education campaign; increased opportunities for organ and tissue donation registration through federal transaction channels; and we recommend that we help the provinces activate their provincially supported teams by making it expeditious and doing so through a nationally supported program that promulgates Canada's existing leading practices.

Thank you.

● (1600)

The Chair: Thank you very much.

That completes our opening statements. Now we'll go to our seven-minute round of questions, and we're going to start with Ms. Sidhu.

Ms. Sonia Sidhu (Brampton South, Lib.): Thank you, Mr. Chair.

Thank you to all our witnesses for being here today.

We heard that only 20% of Canadians sign up as donors, while many more support the idea of organ and tissue donation, but don't sign up. Trillium Gift of Life Network, you said the federal role is supportive. What role could a national public awareness strategy play in promoting organ and tissue donation in Canada? We have an organization in Brampton, Amar Karma, and you have your own organization, but what kind of federal role? You mentioned some, but what are some barriers at the federal level? What more can we do?

Ms. Ronnie Gavsie: Yes, 90% of Canadians say they believe in organ donation and only 20% have registered. Some of the reasons why this is the case are myths. Some people think they are too old, but age is not a factor. Maybe they believe their religions don't support it, which is untrue. Religions do, in fact, I think it's an obligation to save a life if you can. Some think that preceding illnesses would preclude them from donating, which is not the case. Every one of us would be tested for medical suitability. The biggest barrier is procrastination. They don't want to think about it today, and they procrastinate until they are jolted.

Yes, Ontario does a great deal to raise awareness with Amar Karma, as you said, as does B.C. and Quebec. All of the provinces, in fact, have provincial initiatives for public awareness. Still, there's only 20% registration. What none of us has provincially is the authority or the funding for multimedia, television, print, and radio ads with hard-hitting, sustained, persistent education. That is what Spain, for example, and other top jurisdictions have found works for them. We say that we could do this once, develop and implement once, using national media opportunities supported by the federal government: a hard-hitting, consistent, sustained public education campaign.

● (1605)

Ms. Sonia Sidhu: To Dr. Levy, do you have any idea what the federal role is and how we can do more?

Ms. Amber Appleby (Acting Director, Donation and Transplantation, Canadian Blood Services): Just to clarify, is that also in regard to the same question?

Ms. Sonia Sidhu: Yes.

Ms. Amber Appleby: I think Ronnie is correct in that we do really need to look at creating a culture of donation. Really, we don't want donation to be an afterthought. I think all of the opportunities that make it most convenient for people to have many interactions with that opportunity would definitely facilitate an increase in people registering their decisions. I think also, to the point around education and awareness, that we really do want to dispel certain myths. So as part of that campaign, we would want people to understand that it doesn't affect the care that they receive in an ICU or if they're admitted to an emergency department. Those are the types of things that we need the Canadian public to be aware of.

Ms. Sonia Sidhu: Thank you.

My questions are to Dr. Levy. How do Canada's live and deceased donor rates compare with those in other countries? How do you sum up their approaches that are different from ours?

Dr. Isra Levy: We sort of run the in middle of the pack when you look at national comparatives that are similar to us. We've heard the example of Spain, which for deceased donation is about double our rate. However, we're doing reasonably well, certainly when you look at improvements over time on deceased donation. We compare reasonably favourably with the United Kingdom. We compare reasonably favourably with Australia. It does depend what the comparisons are. International comparisons are useful because they force self-reflection, but they have their limitations. We can look at best practices elsewhere and we can learn from them. But really, in comparing ourselves to the United Kingdom, the geographical dynamic is completely different, and the challenge with access to institutions depending on where you live is obviously different by definition. So there are limitations to what one can gather.

The same applies for living donation. There again, we compare reasonably favourably with some of the comparators. There might be less to learn from international comparisons, but I think actually the real value of those comparisons at this point is to set for ourselves some targets, to say we know it can be done better and ask of ourselves why we can't achieve the improvements.

I think we've heard the recipes themselves, so to speak, very clearly articulated by both British Columbia and Ontario, the kinds of things that are needed at the local level to achieve those kinds of rates.

Ms. Sonia Sidhu: Thank you.

Is there any shortage of particular organs?

Ms. Amber Appleby: There are shortages of organs across the board in every single—

Ms. Sonia Sidhu: Are there any particular organs that we need?

Ms. Amber Appleby: I wouldn't say it's one more than another. Wait-lists per province differ substantially depending on the type of organ that's needed and also depending upon a number of other factors, including how highly sensitized a patient might be, for example. That's why we have looked at what the opportunities are—when we know we have such a scarce resource—to share that resource across Canada, to look for the best match.

When there's an opportunity and you have someone on the wait-list who's really hard to match, irrespective of the wait-list, they may actually wait longer if they don't have a larger pool from which to receive from a donor. That's why we're doing things like sharing organs across Canada, for example, because that expands the donor pool from which somebody can actually receive a transplant, and that does impact our wait-lists. An individual's wait time on the list will differ based on a number of factors. That's why it's difficult to say.

Ms. Sonia Sidhu: Thank you.

The Chair: The time is up.

Now we go to Mr. Webber.

● (1610)

Mr. Len Webber (Calgary Confederation, CPC): Thank you, Mr. Chair.

I want to begin by just giving my heartfelt thanks to the committee for allowing this study to happen. It really means a lot to me, through personal experience. I just thank you sincerely for allowing this study to happen. I can't say any more than that. It really means a lot.

I would also like to thank our witnesses for being here today and for the wonderful work you do. I can't thank you enough either.

One reason we're having this study is that we need to know what we can do as a federal government to improve the system here in Canada. Of course, your presentations today gave us some very good recommendations. Thank you for those.

I have a lot of opportunity to ask questions, so I'm going to start with Ronnie Gavsie who made some comments here. One of her comments was on Spain and how well they're doing there. Even though there is presumed consent there—the opt-out type of system—you gave credit, and they gave credit, mostly to media and public education.

With respect to Canada, our public education, and what the federal government is doing to participate in a national awareness campaign, is there anything right now that is occurring from the feds other than, of course, from Canadian Blood Services? Is there a significant amount of money being put into education and media education? Maybe you could just talk a bit about that, and of course, I'd like to hear from Canadian Blood Services as well.

Ms. Ronnie Gavsie: Thank you. I will ask my colleagues at Canadian Blood Services to address part of that question.

In Ontario we do invest, as other provinces do, in promoting stories, statistics, successes, and challenges, to the media, but we are unable to utilize regular, ongoing television opportunities, radio spots, regular series, as such, or full-page ads that would catch people's attention.

A few years ago, we sent a group of physicians and Trillium staff to Spain. They described how, when they arrived at the airport, there was a huge sign, right there at the airport, in their faces, promoting organ donation. Every day that they were there, they'd look in the newsstands, and lo and behold, there would be something on organ donation. It was a tremendous source of pride to people in Spain—apparently along with their soccer team—that they were the best. They were known to be the best in organ donation. That pride translates into consent.

Mr. Len Webber: Do you, personally, believe in an opt-out system, Ronnie?

Ms. Ronnie Gavsie: I believe that if the infrastructure on the ground were in place, if we were all very sophisticated on the ground with our teams, at that point, there may be some added advantage to presumed consent. Until that time, it is not a silver bullet.

Mr. Len Webber: I have a quick question to Canadian Blood Services, Dr. Levy and Ms. Appleby. I've often seen many advertisements throughout travels in Canada, both on billboards and on TV, regarding blood donation. Is there anything being done with regard to media and organ donation?

Dr. Isra Levy: Thank you. I'll start. To be specific, Health Canada helps our work at Canadian Blood Services to the tune of $3.58 million a year. It's not insignificant at all. It's a tremendous support to us. That resource supports a number of different activities. A lot of the work that we do with that money is leading practice development, that is, clinical best-practice guideline development, which is an underpinning of the interprovincial work, and it helps clinicians at the bedside.

We also use that work for data collection and national performance reporting, which as I've explained does help move things along. It depends on whether you're looking at the glass half... one way or the other, as to whether what's left is a lot of money or not. We're grateful for what we are able to spend on national clinician, health professional, and public education. Could we do more if there was more? For sure, we could.

Within Canadian Blood Services, do we do enough cross-promotion of our donation opportunities and requests of Canadians? That's something for us to reflect on, and we do on an ongoing basis. We could probably improve those opportunities ourselves, and if there were further resourcing for more opportunity, we would make use of it.

● (1615)

Mr. Len Webber: You would.

Dr. Isra Levy: Absolutely.

Mr. Len Webber: A question for our friends in B.C., and also Ms. Gavsie, with regard to a recent media report in Ontario that suggested that about 20%, or one in five, of registered organ donors are having their final wish overturned by their family members at the time of death. Is this accurate in Ontario? I'd like to know what the statistics are in B.C. as well.

Ms. Ronnie Gavsie: Shall I start? It's not 20%, but it is between 10% and 15%. It occurs typically in situations of donation after cardiac death. This is a situation where an individual is on life support and the medical team and the family together make a decision to withdraw the life support. Where the family is gathered around their loved one's bedside and the decision is made to withdraw life support, in many cases they will say, "We want to do it now. We are all here. We've been through a lot together. We want to say our good-byes and we want to do it now." When that happens, which is not uncommon in donation after cardiac death, it will happen right away. This does not give us the opportunity to put the process in place for donation.

Mr. Len Webber: In B.C., as well, please, I'd like to know what is happening there with respect to the families saying no.

Ms. Leanne Appleton: This is very rare in B.C., so we don't know where that figure came from. As Ronnie was just saying, it usually has to do with something related to the family feeling very overwhelmed in a very tragic situation and wanting something to happen very quickly, and we're not able to mobilize.

I'd like to clarify as well that if someone did not register their decision, we do ask the family. Likewise, if someone registered and said no, we do ask the family if there were any recent conversations in which the loved one would have had a different decision. We do ask that of the family. We respect their wishes, but we do ask that follow-up question.

Mr. Edward Ferre: The registry that we have is both a consent registry and a dissent registry, so we have that obligation to speak with the families to ensure that we're capturing the loved one's decision.

The Chair: Okay, thanks very much.

Mr. Davies.

Mr. Don Davies (Vancouver Kingsway, NDP): Thank you, Mr. Chair.

Thanks to the witnesses for being here.

Ms. Appleton, I'm from Vancouver, so I'm going to direct my first few questions to B.C. Transplant, if I may.

A new program encouraging customers of the Insurance Corporation of British Columbia to register as organ donors has boosted the donor list by more than 15% in a single year. ICBC reports more than 125,000 customers have registered with B.C. Transplant as potential donors since driver licensing employees began asking customers last year to make their wishes known.

Could you elaborate on the success of that program?

Ms. Leanne Appleton: Yes, we'd be happy to, and thank you for raising it.

This is creating another touchpoint for British Columbians. As they come in to register, get their driver's licence renewed, those customer representatives have been educated through a fulsome program by B.C. Transplant and our community outreach professionals, and they take pride in having those conversations with British Columbians. It is creating another opportunity in a proactive way to have those conversations. Sometimes individuals need more information, and we dispel myths right at the counter. Other times they want to go away and think about it, and they can register online, but we find a lot of British Columbians take action when they come in at that time. We have had tremendous success with this partnership.

● (1620)

Mr. Edward Ferre: When you look at our registration program, in a five-year cycle you'll have touched every person in the province who is renewing their driver's licence, so it's a very good mechanism to touch as many in the population as we can.

Mr. Don Davies: Thank you.

I also know B.C. Transplant has made a concerted effort in recent years to reach out to certain ethnic communities, including having its volunteers attend various community festivals and translating your outreach materials into Punjabi and Chinese. Can you update the committee on the effectiveness of those outreach efforts?

Mr. Edward Ferre: We have quite a significant immigrant population in British Columbia, and not only are those individuals eligible to donate, but a number of them are on the wait-list. We work with the individuals, with the volunteers in those groups, in those ethnic groups, to help educate their groups in any way we can, through meetings of their social groups or their religious affiliations, and we're finding that more and more individuals who immigrate to B.C. are registering on our donor registry. That is the one thing that we drive them to, to be able to acknowledge that this is something they would like to do.

Mr. Don Davies: Thank you.

I have one final question for you.

Mr. Levy commented on the issues of regional discrepancies in organ donation. In 2014 at the *Vancouver Sun*'s request, B.C. Transplant provided data on the number of people on its registry in every postal code of the province. The*Sun* then compared that against population figures from the recent census and the data showed overall about one in five B.C. residents were on the registry but that rates varied greatly depending on where people lived.

In your view, what explains that variation, and what steps, if any, has B.C. Transplant taken to close the regional registration gap?

Mr. Edward Ferre: One of the things that is increasing the number of registrations, that is equalizing it more, is where the Service B.C. locations are found. A lot of them are in the rural areas. When you look at a sparsely populated area, you'll find that they probably have very high rates of donation because there is a smaller population and all those people can somehow be brought in to register at these Service B.C. stations.

In Vancouver, in the urban centres, it's a little more complex. A lot of them have to do with the ethnic populations, and what we're following and what we've found is within the ICBC drivers, that is increasing those registrations where typically we saw low numbers.

Mr. Don Davies: Ms. Gavsie, my information, if I'm not mistaken, is that at least 24 European countries have adopted some form of a presumed consent system for organ donation, and you have mentioned the prominent systems in Spain—I think they are also in Austria and Belgium—that yield very high donor rates.

You also mentioned that the number one enemy to organ donation registration was procrastination. Would it not work in reverse? If everybody was presumed to donate, would that then not bring the same level of procrastination to opt out, that they would in reverse.... Wouldn't a presumed consent system be a very strong way that we could get more people registered and count on that age-old human condition of procrastination to carry the day?

Ms. Ronnie Gavsie: Certainly, intuitively it would seem to us that it's a silver bullet. However, when we research the matter and go to the other jurisdictions, we find out that it's not, because the family is still—in all of those countries—required to consent, and because of presumed consent they would never have had the discussion. There's no trigger or reason for a family to have ever discussed it, so the families will say they don't know that their relative really read the small print and understood that he was defaulting to yes and they don't think he would have wanted it.

We recently had visitors from Singapore who've had presumed consent for a decade, and they came to find out how to increase their donor rate. France—you would have read about this a few months ago in the paper—sounded as though they were putting in presumed consent. They have in fact had presumed consent since 1976. What they are doing is putting in a requirement for the family, if they will not consent, to bring a signed paper from the person who passed away saying that he or she did not agree to be a donor.

Although intuitively it sounds as though it would be the answer, empirically it has not proven to be.

● (1625)

Mr. Don Davies: Thank you.

The Chair: Mr. Oliver.

Mr. John Oliver (Oakville, Lib.): Thank you very much for your testimony.

I do want to thank our colleague Mr. Webber for bringing this topic to our attention and making sure we made time for it in our meetings. Thank you for that, Len.

I have the recommendations—I'm just trying to capture them—that you've made in terms of what we could be addressing: develop and implement a sustained multimedia campaign to promote donors, develop a strategy to administrate and manage interprovincial organ sharing, and increase the opportunities for donor recognition, particularly in federal documents, tax forms, or Service Canada.

I am a bit fuzzy about supporting a system across Canada that prioritizes these initiatives. I wasn't quite sure what that was about. Could you just elaborate on that one again, Ms. Gavsie?

Ms. Ronnie Gavsie: Yes, certainly. I'll do so using an example, if I may. It's already been acknowledged this afternoon that British Columbia's living kidney donation program is recognized across Canada as being best in class. The recommendation is that all the details surrounding that program be packaged and moved across the country.

Mr. John Oliver: Okay, so it's an adoption of best practices as they emerge, rather than reinventing it.

Ms. Ronnie Gavsie: Rather than creating something new I think if you went to various different provinces you'd find they are centres of excellence.

Mr. John Oliver: It's recognizing and adopting best practices as they emerge.

Ms. Ronnie Gavsie: Correct.

Mr. John Oliver: There's a bit of a darker side to the shortage of organs, which is the buying, selling, or trading of human organs. As I understand it right now, the Criminal Code in Canada doesn't prohibit that activity, and I was just reading that Canada's in the top 10 of global importers. Most of it's done through transplant tourism whereby people leave, go to another country, receive an organ, and come back with it, so they're importing it already transplanted.

I'm worried about the consequence of that in some countries where the socio-economic realities might lead people to...with wealthier countries adopting or taking organs from other people based on an economic transaction.

Do you think more needs to be done there? Is that an area of concern to any of you? Do you think there should be something stronger in our Criminal Code to deal with the buying, selling, or trading of human organs?

Ms. Amber Appleby: Obviously, while I can't comment on legislation and what should or shouldn't be in place, what I can comment on is that within Canada I think we do a really good job of making it clear that we do not support those practices.

Mr. John Oliver: Okay.

Ms. Amber Appleby: We are faced with the reality that, from time to time, people will leave the country and they will receive organs outside of the country and they will come back. That's something that we are forced to reconcile when they do return, in terms of ensuring that they receive the optimal post-transplant care.

Mr. John Oliver: Would any of you recommend that this committee make a recommendation around that, that at the national level we recommend restrictions on that kind of trade?

Dr. Isra Levy: We haven't done a legal analysis of the implications, but from an ethical point of view we clearly abhor that behaviour and would support in principle strongly conveying that piece.

● (1630)

Mr. John Oliver: Thanks very much.

On the strategies to advance interprovincial organ sharing, I noticed in our analysis from our librarian that Saskatchewan, New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador, the Yukon, Northwest Territories, and Nunavut do not at this point maintain registries. They have vehicles so people can identify themselves as donors, but there is no registry of them so it's harder to track and harder to find them.

If we look at interprovincial sharing agreements, does there need to be at least a national agreement among the provinces and territories around the maintenance of a registry? You would think that would be a minimum start.

Ms. Amber Appleby: I want to make a point of clarification. I think the registries you're speaking of are very different. The intent-to-donate registries are operated provincially. You're correct. Some of them have more paper-based systems. Each province needs to look at that and decide what they need to do about that situation.

The interprovincial organ-sharing programs that are operated nationally by CBS have interprovincial sharing agreements already in place. When we say expanding them, what we mean by expanding those registries is not to be confused with the other registry. We're looking at expanding them to other organ groups.

We talked about highly sensitized patients. Right now we're exchanging kidneys routinely across Canada to improve Canadians' likelihood of receiving a kidney transplant. We need to do that for other organs. If a patient is sensitized, we need to start to put in place heart-sharing agreements, for example.

Those are some of the things we continue to work on.

Mr. John Oliver: That's not necessarily the donor. It's the organ itself, and who would benefit from it best.

Ms. Amber Appleby: That's right.

Mr. John Oliver: Prioritize that nationally. Thank you for that.

I noticed by law all deaths in designated facilities such as hospitals must be reported to the Trillium Gift of Life Network. I think that came in recently. I used to be a hospital CEO. I remember implementing those changes.

You mentioned running the on-the-ground teams. That was a phenomenal add. It was very difficult for the doctors and nurses in the ER or the ICU to have that type of conversation. Now with the reported death, they would simply pass on the family contact information to your agency who would then initiate the call, have the conversation with the family, and if they were willing, the harvesting team—they don't call it that any longer—would go through the procedure and support the family. It was a real value-add to the local facilities.

Is the duty to report just Ontario, or is that Canada-wide? Is there any work on replicating those on-the-ground teams across Canada?

Ms. Amber Appleby: You're right in that the legislation differs provincially. I will have to double-check, but I believe right now five provinces have mandatory referral written into their current legislation. It's also important to note that even the mandatory referral legislation differs provincially. For example, in B.C. there is a requirement to report all deaths of those younger than 75.

The way the legislation is currently written is quite different, and a few provinces still do not have mandatory referral legislation. A couple are in the process of getting it, that don't yet have it in place. It would be very helpful to ensure that was in place in every jurisdiction.

The Chair: Your time is up.

Now we go to Mr. Webber for a five-minute round.

Mr. Len Webber: Thank you.

I thank my colleagues for allowing me to continue with my questioning. I will share a bit later on.

Dr. Levy, in your presentation you suggested that the federal government could perhaps be involved in developing strategies for organ sharing among the jurisdictions here in Canada. Of course, there are technologies out there. Cryopreservation and ex vivo technologies allow organs to survive outside a body for three to five days. I have seen these machines where you can see a heart pumping away, or lungs expanding and contracting. It's amazing.

What is occurring right now throughout Canada with regard to the sharing of organs? Is it strictly B.C. and Alberta that share within themselves, or is there sharing throughout the country?

● (1635)

Ms. Amber Appleby: The first priority is usually provincial allocation when it comes to organs. There is a big focus on provincial self-sustainability there. The reasons we usually share organs outside of a province are a few different cases. One is when you have a medically urgent patient somewhere else in the country and you need to prioritize them, typically somebody on a ventilator in an ICU and they will die without the organ. We prioritize those. We also prioritize hard-to-match patients. That's what I referred to in terms of highly sensitized patients. There are a number of other cases, not just highly sensitized, where patients are hard to match.

Those are the types of programs that we're trying to advance in terms of sharing the organs. Typically, it's within jurisdiction first. Then also to maximize utilization of organs that are donated, if a jurisdiction can't use that organ because it's not the right size, not the right match, or not the right patient, we will take those non-utilized organs and we will share those across the country.

Mr. Len Webber: Is there co-operation amongst the provinces and territories with regard to allowing to give if it's more required over here? Are there any instances of "No, we're keeping it; we need it here"?

Ms. Amber Appleby: We have established agreements nationally whereby we have agreed when we're going to share organs. For example, with our HSP program, which is currently highly sensitized for kidneys, we have an interprovincial balancing threshold that's within our IT system that says you are required to give one of the kidneys to the national list first and then this one can be allocated provincially. Those are the types of agreements. We work really hard with our clinical community to come up with what makes sense and also to make sure it's not inequitable when we actually are sharing organs.

Mr. Len Webber: Ms. Gavsie, you mentioned the need for increased opportunities on the federal level with respect to channels to registration. I would be remiss if I did not mention my private member's bill that is coming forward here very soon, Bill C-316, which if it is passed, would allow Canadians to indicate their desire on their income tax forms of whether they would be organ donors. I have many official seconders from all parties, including numerous individuals in this room.

Thank you for that.

There are 25 million Canadians who file taxes annually. Can you comment on this proposal, all our witnesses, and what impact you think this would have? Do you see it as a positive thing? Do you see any concerns with this bill?

Ms. Ronnie Gavsie: I think it's a very positive thing. Registration has been proven to be transaction-based, and that's a transaction where you have millions of Canadians. What would simplify the process is, rather than having them register on their tax returns, a requirement for them to go through CRA to the home province's mechanism for registering, thereby not needing to move personal information through a different channel.

I certainly do, and we do at Trillium, support that concept and believe it would go a long way to increasing the consent rate.

The Chair: We go to Mr. Ayoub.

I suspect this question might be *en français*.

[*Translation*]

Mr. Ramez Ayoub (Thérèse-De Blainville, Lib.): Thank you, Mr. Chair. After two and half years, you now know that my questions will indeed be in French.

First, I want to thank all of you for being here with us.

This is an extremely interesting topic. Whenever we do research, we learn a lot of things. As you have all mentioned, we can do better.

The research I did about the increase in the number of donors, and the questions I put to several other witnesses from Quebec, British Columbia and Ontario, allowed me to discover that a lot of work is done in isolation. Everyone does the best possible work, since we have considerable expertise, but my impression is that expertise is not always disseminated in an accessible and user-friendly way. In fact, several meetings are held to share information, but certain measures may not be taken, or perhaps there are things that remain to be done.

I'd like to understand a bit better and see if I am mistaken. How do you see things from your side? Have any actions been undertaken? What are your priorities to increase the number of donations and the success rate of these donations?

As we know, not everyone is a compatible donor. I am not going to name anyone, but someone told me that we had almost already reached the annual maximum number of potential donors, and this disturbed me a bit. I told myself that if that is the case, even if we reach the ideal number of donors, 200 to 225, there would still be 4,000 people on the waiting list.

How can we combine all that and reach a result that will allow us to save as many lives as possible? The primary purpose is indeed to save as many lives as possible through organ donations from living or deceased donors.

I've talked enough. I'm going to give Mr. Levy and the others a chance to answer.

● (1640)

Dr. Isra Levy: Thank you very much.

I'm sorry, but I'm going to continue in English. Thank you.

[*English*]

Mr. Ramez Ayoub: You can answer in English. I don't have lots of time, so—

Dr. Isra Levy: Yes, it would take time.

First, thank you very much. I do not believe that we're close to the maximum. I think there is a strong opportunity for improvement. I think the kinds of things that we've heard, particularly from our provincial program colleagues today, give us a very good focus on where some of those opportunities can be. Clearly, we can improve the registration rate. We can improve the clinical work that gets done in terms of best practices and in terms of coordination.

Our priorities at Canadian Blood Services will continue to be on exploring how some of the information technology work and infrastructure that we've built with the provincial and territorial infrastructure for organ sharing can be leveraged by machine learning as we partner with the clinical community and the provincial programs to improve on the cross-jurisdictional sharing. I think we have the elements in place, but we can't become complacent. We do need ongoing attention. The kind of study that's being done here, the kinds of ideas that have been put forward will make a difference, and we should keep that up.

I'll ask my colleague to comment further.

Ms. Amber Appleby: In terms of some of the very specific things we're doing to improve collaboration and help each other as a system, we have a group that meets regularly and that shares practices from one jurisdiction to another. We do that actively. Every year we get together and come up with our biggest national priorities that we want to work on together to improve performance, recognizing that some provinces may be focused on other things as well. Where they have incomplete adoption of DCD, that may be their primary focus right then, and that's okay. We always share freely.

One of the things that we're most focused on now in terms of a priority is really addressing what you just brought up, which is looking at what our donor potential really is. We need to ensure that we have mandatory death audits across Canada, in every single jurisdiction, that are as real-time as possible so that we can really understand what our potential is and whether we are missing opportunities.

We know that donors can be lost at any point along that clinical pathway, so we need to be auditing that pathway and making sure that where we're losing donors, we are fixing whatever system issues are preventing us from actualizing that donor. We have done a lot of work in that realm together, including donor identification and making sure we have consistent national clinical triggers so that people know when to refer a donor. We've been doing a lot of things like that in terms of leading practices, where we're sharing that knowledge across the country.

● (1645)

Mr. Ramez Ayoub: Thank you.

The Chair: Your time is up in English or French.

Ms. Gladu.

Ms. Marilyn Gladu (Sarnia—Lambton, CPC): Thank you, Chair.

Thank you to the witnesses.

I want to follow up on my colleague's question because we ran out of time. His Bill C-316 will give everyone the opportunity to opt in on their income tax form as an organ donor. I'd like to hear from my friends in B.C. Do you think this is a good idea, and is there anything you would add as an improvement?

Ms. Leanne Appleton: We certainly welcome any time there's an opportunity to have another touchpoint for Canadians to consider organ donation and register their wishes, yes or no, so their families are aware of those wishes. Certainly we would want to ensure this specific bill is done in a very thoughtful manner so there's very explicit education to Canadians across the country that this is going to be a change. We would want anything to enhance this, so we would not want this to detract from how people feel about their tax return. We want to make sure this is done in a very methodical way, with lots of education, and certainly making sure it's an informed consent. Do they know when they're saying yes, and do they know if they're saying no, that it's an informed consent?

Ms. Marilyn Gladu: My friends at Canadian Blood Services, I have the same question.

Dr. Isra Levy: Just like our colleagues, we support a transactional touchpoint that will raise awareness, especially if it leads to the conversation. I think the comments my colleague from Ontario made with respect to being sensitive to the provincial systems this will feed into is an important nuance to things. But for sure this is to be welcomed.

Ms. Marilyn Gladu: That's great.

The other thing I want to talk about is the portability of people.

People are working across the country. Maybe they're originally from Newfoundland and they're working at Fort McMurray and they're moving out there. What kind of communication or sharing of information happens across the provinces? If they get into an accident while they're out there, would you know they're an organ donor? How does that work, especially with some of these provinces that, as you mentioned, are on a paper system?

Ms. Amber Appleby: There are a couple of questions there. One would be, what happens when you move to another province? The way it works right now, yes, you would have to re-register your intent to donate wherever you move to. To try to make that easier we've created a national microsite, where you can go to one spot. That will help direct people who don't know where to go in their own province or what the process is. We do have that in place.

The challenge would be if you pass away in a different province, and you have the opportunity to be a donor. Usually the next of kin would be approached to understand what your wishes would have been. I believe the next of kin could ask their provincial registry with regard to that information.

Ms. Marilyn Gladu: All right. You talked about how it's provincial jurisdiction for the registry of those who want to donate, as well as for the registry of those who need an organ. For the provinces that don't have anything in place, could the federal government be of help by promoting funds or something so they could get the kinds of databases that the very successful B.C. and Ontario examples have shown?

Ms. Amber Appleby: In terms of IT infrastructure, so that I'm being really clear, within each provincial jurisdiction, you're right, some do have IT systems for intent-to-donate registries. Those are strictly provincial systems that are intent-to-donate only. They're not the same as listing a patient for a transplant. The opportunities lie within each jurisdiction.

For example, some provinces don't have local listing and allocation IT systems. That could be put in place to support those activities provincially, and have that linked to the national system. We do have a national IT system for allocation of organs, and we also have a national system for wait-listing the urgent patients. Again, there is variability in what exists in every province, and there is probably an opportunity to look at what could be done there to assist those local systems that don't have that in place.

Ms. Marilyn Gladu: Is there anything else the federal government should be doing to remove the barriers that exist to people becoming organ donors?

Ms. Amber Appleby: I think what's been said a couple of times is just in knowing and understanding the complexity of the system. Public education and awareness is really important, but equally if not more important is professional education and awareness. I think this is one of the learnings as well from Spain, and how they have professionals at every level within their health care system who truly know and understand the intricacies of what's required to facilitate donation. It's a focus on all those things because you have to have highly trained professional people at the ready to respond to the donation opportunity. I would think that would be another key area of focus.

● (1650)

The Chair: Your time's up.

Dr. Eyolfson, you have five minutes.

Mr. Doug Eyolfson (Charleswood—St. James—Assiniboia—Headingley, Lib.): Thank you, Mr. Chair.

I'd like to thank Mr. Webber for bringing his bill forward and also for wanting to do this study. I agree it's quite worthwhile.

This is near and dear to my heart for different reasons. I practised emergency medicine for 20 years. Unfortunately, I had to have this conversation with families a number of times. I worked in a trauma centre. We saw lots of gunshot wounds and motor vehicle accidents, hence many potential donors. I agree that there are barriers we need to overcome to facilitate this.

I guess the best way to say this is, maybe, to change gears on this. One of the things we like to look at, as well, is prevention. We do know that you can take a burden off any system from both ends, from the supply but also the demand side.

I'll go through each group in turn. First of all, to our friends in B. C., can you pinpoint any diseases or processes that you would say really stand out as causes of people needing organs—for example, diabetes causing kidney failure, alcohol causing liver failure, or anything like that? Are there any disease processes that stand out that, if addressed better, would decrease the need for organs?

Mr. Edward Ferre: Yes, especially with renal failure. We have an aging population. All of the diseases, such as diabetes and hypertension, which are very prevalent in our society, contribute to this so that we're seeing increased numbers of people on the list.

On the donation and transplant end of things, we really encourage living donation. We're looking at a process now, which we call pre-emptive donation. If a patient is seen by a nephrologist and may be moving toward the trajectory of dialysis, we can intervene at that point in time, and they can find a living donor and get transplanted before they need to go onto dialysis, saving the health care dollars in that sense, but also there's a lot less wear and tear on the patient.

Mr. Doug Eyolfson: Thank you.

What about our friends from Canadian Blood Services?

Dr. Isra Levy: Thank you. In a former life I spent a lot of time thinking about prevention at the end of the spectrum that you're referring to. I'm grateful for the question.

The classical remediable, preventable causes of chronic disease come to mind right away. We know them to be alcohol, tobacco, and obesity issues. Do those drive donation need? I don't have the epidemiology to back that up, but I would say instinctively that, just as you said diabetes, clearly I think another one to think about is misuse of prescription and non-prescription medication. Certainly I'd be questioning whether acetaminophen is a part of the underpinning of some of the organ failures where we see the need. I think it's a very good way to go to think about some of the interventions that can switch off some of the demand side.

We tend not to do the epidemiological analyses of the registries through that angle, through primary remediable cause. Certainly, we know what causes chronic illness.

Mr. Doug Eyolfson: Ms. Gavsie, do you have anything to add to that?

Ms. Ronnie Gavsie: Two-thirds of the Ontario wait-list are people waiting for kidneys, and it has been that way for many years. If you were to ask us, based on our experience, where your support is needed, I would say it's prevention of diabetes.

Mr. Doug Eyolfson: Okay, thank you. That's very useful.

I'll start with you, Ms. Gavsie. I might only have time to start with you—I have less than a minute left. I was privileged because I worked in a large teaching centre. We had all this infrastructure. We always had our radar up about organ donors. You'd get primary care practitioners in more isolated centres, low-volume centres, who might not realize that certain kinds of patients could be organ donors. They're more than just car accidents and bullet wounds. There are a number of conditions in which patients can be suitable as donors.

Have you been reaching out to the medical profession and medical education so that medical professionals know all of the indications or suitable types of patients for organ donations?

● (1655)

Ms. Ronnie Gavsie: We have worked with the Royal College to develop e-books for physicians coming into critical care, for residents in the critical care unit. In addition, in Ontario we have 58 donation physicians who are accountable to us, including in all of the smaller hospitals, not just the large trauma centres, such that we get referrals of an amazing number of potential donors from these smaller hospitals.

Mr. Doug Eyolfson: Thank you.

The Chair: Now we have three minutes with Mr. Davies.

Mr. Don Davies: In three minutes, I have two short snappers and a tough one.

Does anybody know and can anybody tell me whether the buying and selling of organs for transplantation—we know it's prohibited—is a Criminal Code matter or is found in provincial statutes? Does anybody know? No?

Okay. Here's number two.

Mr. Levy, you gave I think a very articulate expression of the strong ethical opposition to the selling and purchasing of organs and tissues. Does the same rationale apply to the purchasing and selling of blood and blood products?

Dr. Isra Levy: I think I would say that the issue is situation-specific, product-specific, and context-specific. Purchasing in the context of transplantation tourism is what I was responding to, but in the broader context, I think the ethical underpinnings of different scenarios would need to be thought about in their own domains.

Mr. Don Davies: There's border tourism, but surely you wouldn't be in favour of Canadians being able to purchase and sell organs to each other on the commercial private market, would you?

Dr. Isra Levy: I don't know. I haven't conceptualized it, but the context in which the question was asked, or at least that I was responding to, was tourism.

Mr. Don Davies: Okay. Thank you.

The tough one is for you, Ms. Gavsie. There was a pretty prominent case of a Trillium Gift of Life decision to deny Delilah Saunders, who had acute liver failure and was in a Toronto hospital in December, access to a life-saving liver transplant. As we understood it, I think Trillium requires patients with alcohol-associated liver diseases to be alcohol-free for six months before being accepted as potential patients.

Amnesty International wrote the following in an open letter to you:

> ...states have an obligation to guarantee the right to the highest attainable standard of health of all individuals, free from discrimination. To deny individuals access to necessary and lifesaving medical treatment purely on the grounds of their prior or current health status—including conditions resulting from the use of alcohol—is discriminatory.

It goes on to talk about requesting a change to that policy.

I know it's a very difficult ethical issue, but has there been thought about or any change to Trillium's policy in regard to people who may be suffering from substance abuse disorders and needing transplants?

Ms. Ronnie Gavsie: I'm pleased to respond to that difficult issue. There is an alcohol-related liver disease pilot program that is about to be launched, a three-year pilot, which will tell us whether or not there's evidence for a better policy than the six-month rule, the six-month rule being the one that is used internationally. It is the most common rule.

We're all happy that Ms. Saunders was assessed. In other words, the six-month rule does not stop someone from being assessed. They are not just automatically not put on the waiting list. She was hospitalized. She was assessed. She received medical treatment and went home. She didn't need a liver transplant. The outcome of that situation was a happier one.

On the six-month rule, there is no scientific evidence that six months is the right number. In some cases, it might be two months. In the case of other people, it might be two years. This pilot program, which is being supported by the province, will give us evidence as to whether, when the individuals receive the right therapies and support from social workers and addiction specialists, the six-month rule may no longer be applicable. We'll have evidence as to whether there's a different, logical rule.

● (1700)

Mr. Don Davies: Thank you.

The Chair: That completes our testimony for today.

I have two thoughts. First of all, on behalf of the committee, I want to thank you for what you do. I think you're amazing in what you do, and I hope our committee can give you a little bit of help to do it.

My second thought is that we deal with the most fascinating things here, but they hardly ever have a predictable outcome, and this could have a predictable outcome. If we could help you raise public awareness and professional awareness, it would have a predictable outcome. For so many things we deal with, we don't really know how they're going to turn out.

This might help or it might not. There are differences of opinion. I'm sure the committee members will put our heads together and see if we can't come up with some ways to help, but I want to thank you for your testimony, and again, I want to thank you on behalf of the committee for what you do.

Ms. Ronnie Gavsie: Thank you.

The Chair: We're going to adjourn for a few minutes. Then we're going to go to committee business in camera. Thanks again.

[*Proceedings continue in camera*]

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